

DOCUMENT RESUME

ED 332 411

EC 300 273

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TITLE Making the System Work: An Advocacy Workshop for Parents. Families as Allies Project.
INSTITUTION Portland State Univ., OR. Research and Training Center on Family Support and Children's Mental Health.
SPONS AGENCY National Inst. of Mental Health (DHHS), Rockville, MD.; National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE Sep 87
CONTRACT G008435137
NOTE 58p.
PUB TYPE Guides - Classroom Use - Teaching Guides (For Teacher) (052) -- Tests/Evaluation Instruments (160)

EDRS PRICE MF01/PC03 Plus Postage.
DESCRIPTORS Assertiveness; Change Strategies; *Child Advocacy; Elementary Secondary Education; *Emotional Disturbances; Learning Activities; *Parent Education; Parent Rights; Parent School Relationship; Problem Solving; Self Evaluation (Individuals); Student Rights; Teaching Methods; *Workshops

ABSTRACT

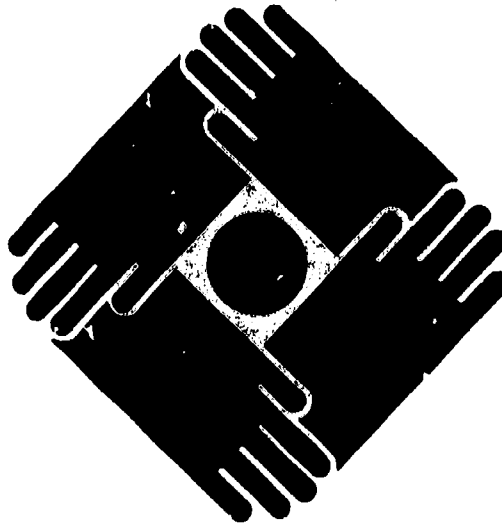
The materials in this guide are for the use of trainers who are introducing the concept of advocacy to parents of emotionally disturbed children. The materials describe a 1-day advocacy workshop led by a facilitator who is familiar with the local school district, community and state mental health systems, and state and local political systems. The workshop includes introductory activities; administration of an assertiveness questionnaire; parent rap session; defining advocacy; role playing effective advocacy techniques; identifying problems, possible solutions, and sources of power to correct problems; identifying assertive/passive/aggressive statements; making effective demands; and analyzing one's advocacy potential. The guide includes a rationale for each workshop component, descriptions of activities, lists of materials needed, and notes on the facilitator's role. The guide also includes self-assessment instruments, handouts for workshop participants, worksheets, discussion questions, masters for overhead transparencies, and a 20-item bibliography. (JDD)

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MAKING THE SYSTEM WORK

AN ADVOCACY WORKSHOP FOR PARENTS



**Families as Allies Project
Research and Training Center on Family Support
and Children's Mental Health
Regional Research Institute for Human Services
Portland State University**

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AN ADVOCACY WORKSHOP FOR PARENTS

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Produced and Distributed by:

**Families as Allies Project
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Services for Seriously Emotionally Handicapped
Children and Their Families
Regional Research Institute for Human Services
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September 1987

This publication was developed with funding from the National Institute on Disability and Rehabilitation Research, U.S. Department of Education and the National Institute of Mental Health, U.S. Department of Health and Human Services (NIDRR grant number G008435137). The content of this publication does not necessarily reflect the views or policies of the funding agencies.

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PREFACE

Parents make effective advocates for their children. They were instrumental in the passage of P.L. 94-142, The Education for All Children Act, and in the development of many community services for children. Politicians at the local, state and national level are well aware of the potency of "Parent Power," and they tend to listen carefully when a group of parents steps forward to advocate for an issue.

Emotionally disturbed children are in need of such advocates. Today there are more than seven million disturbed children and adolescents in America. Although estimates vary, approximately 400,000 are psychotic, 1.8 million are severely disturbed, and 4.8 million have emotional problems and are in need of specialized services. According to one estimate, only 500,000 are currently being treated by the mental health system. These numbers are compounded when we add the millions of anguished family members who must deal with the problems of an emotionally handicapped child on a daily basis.

For their own sake and for the sake of their children, the parents of children with emotional handicaps have to organize, educate themselves and become advocates for the services their children need. This workshop is an introduction to the concept of advocacy. It is intended for a parent audience that is beginning to see the need for advocacy and requires some information about how to get started.

The workshop is most effective if there are between 12 and 40 participants. It is wise to limit the participants to parents, foster parents or relatives of emotionally disturbed children. Professionals should not be participants because their presence may inhibit the parents and negate the purpose of the workshop.

The facilitator for the workshop must be someone who is familiar with the local school district, community and state mental health systems, and state and local political systems. The facilitator's major roles include: (1) providing basic information about advocacy; (2) modeling appropriate advocacy techniques; and (3) encouraging the participants to see themselves in advocacy roles.

The materials in this training guide are for the use of the trainer. The white pages are for workshop participants and can be copied and distributed in participant packets.

MAKING THE SYSTEM WORK: AN ADVOCACY WORKSHOP FOR PARENTS

GOAL: To identify the characteristics and skills of an effective advocate for children and youth with emotional handicaps.

OBJECTIVES:

- 1.1 To define the term "advocacy";
- 1.2 To identify the purpose and value of advocacy;
- 1.3 To identify the characteristics of an effective advocate;
- 1.4 To distinguish among assertive, passive and aggressive statements;
- 1.5 To demonstrate making effective demands;
- 1.6 To identify sources of power and the chain of command in service agencies and educational systems;
- 1.7 To practice different types of advocacy activities
- 1.8 To analyze the individual's own strengths and weaknesses in advocacy.

ACTIVITY AGENDA

8:00 - 8:15	Coffee/Informal Gathering	WHOLE GROUP
8:15 - 8:30	Introductions/Agenda Review	WHOLE GROUP
8:30 - 8:45	Assertiveness Quotient	INDIVIDUAL
8:45 - 9:30	Parent Rap Session	WHOLE GROUP
9:30 - 10:30	What is Advocacy? Why Is it important?	WHOLE GROUP/ SMALL GROUPS
10:30 - 10:45	BREAK	
10:45 - 12:00	Problems/Solutions/Power	SMALL GROUPS
12:00 - 1:00	LUNCH	
1:00 - 1:45	Assertive/Passive/Aggressive statements	WHOLE GROUP
1:45 - 2:30	Making Effective Demands	WHOLE GROUP/ PARTNERS
2:30 - 2:45	BREAK	
2:45 - 4:15	Advocacy Assignments	SMALL GROUP/ WHOLE GROUP
4:15 - 4:30	Self-Analysis	INDIVIDUAL
4:30 - 5:00	Workshop Evaluation	WHOLE GROUP

INTRODUCTORY ACTIVITIES

Materials Needed

Coffee, tea, juice
Cream, sugar
Paper cups, napkins, spoons

Name tags

Agendas

Participant Packets

Overhead projector
Extension cord
Screen

Tape recorder
Cassette Tape

Time Needed to Complete Introductory Activities

(15 min.) Activity A: Coffee/Informal Gathering

(15 min.) Activity B: Introduction/Agenda Review

Activity A: Coffee/Informal Gathering

WHOLE GROUP

Purpose: To establish a friendly atmosphere

Preparation: Have name tags made in advance for all participants with some blank ones as spares. Try to find out a little information about each participant so that you can greet each one personally.

Well in advance of the workshop, assemble all of the handouts for the workshop into participant packets. Folders with pockets are helpful for keeping the papers straight.

Have available one large newsprint tablet and set of markers for each small group (1 for every 4-5 people). Also have available a roll of masking tape to mount newsprint sheets on the wall.

Arrive at least one hour early to prepare coffee and tea and make other arrangements for refreshments. Position the overhead projector and make sure that it is focused. Set up the tape recorder and test the tape to make sure it is working. Fifteen minutes before the workshop is to begin, make sure you are finished with your preparations and ready to greet participants as they arrive.

Activity: Participants register, receive their name tags and packets, and have the opportunity to enjoy refreshments and meet each other.

Facilitator's Role: Make a point of circulating among the new arrivals, introduce yourself and greet everyone. Try to make sure that no participant is left standing alone.

Activity B: Introduction/Agenda Review

WHOLE GROUP

Purpose: To explain the nature and format of the workshop

Preparation: Make an outline of remarks to be made to the whole group.

Activity: The facilitator introduces himself/herself and reviews the workshop agenda, highlighting such housekeeping details as location of bathrooms, breaks, luncheon opportunities, nearest telephone, etc.

Facilitator's Role: Establish from the beginning your credentials for leading this group. Let the audience know about your experience and background. Indicate in every way you can your personal interest in them and your respect for them. Emphasize that the day's schedule is full and activities will move quickly. Reiterate at the close of your introduction the overall goal for the workshop.

ASSERTIVENESS QUOTIENT

Materials Needed

Assertiveness Quotient Questionnaire (from participant packet)
Pencils

Time Needed to Complete the Activity

(5 min.) Explanation

(10 min.) Completion Time

INDIVIDUAL

Purpose: To have each participant analyze his or her own level of assertiveness

Preparation: Assertiveness Quotient Questionnaires should be in each participant's packet.

Activity: Participants fill out questionnaires and save them in their packets.

Facilitator's Role: Give directions for filling out the questionnaire and explain that the questionnaires can be kept private by putting them back in the participant's packets. Tell participants to STOP at the stop sign on the questionnaire. The Action Plan will be filled out later.

ASSERTIVENESS QUOTIENT (AQ) TEST

Test your Assertiveness Quotient (AQ) by completing the following questionnaire. Use the scale below to indicate how comfortable you are with each item:

- 1 -- very uncomfortable
- 2 -- moderately comfortable
- 3 -- very comfortable

- _____ 1. Speaking up and asking questions at a meeting.
- _____ 2. Commenting about being interrupted by another person.
- _____ 3. Stating your views to an authority figure.
- _____ 4. Confronting repair people who overcharge, do not do work or do not show up for appointments.
- _____ 5. Speaking in front of a group.
- _____ 6. Maintaining eye contact, keeping your head upright, and leaning forward in personal conversation.
- _____ 7. Being especially competent, using your authority and/or power without labeling yourself as impolite, aggressive or pushy.
- _____ 8. Requesting expected service when you have not received it (e.g. in a store, restaurant, doctor's office).
- _____ 9. Talking positively about your accomplishments.
- _____ 10. Being expected to apologize for something and not apologizing since you feel you are right.
- _____ 11. Requesting the return of borrowed items without being apologetic.
- _____ 12. Receiving a compliment by saying something assertive to acknowledge you agree with the person complimenting you.
- _____ 13. Accepting rejection.
- _____ 14. Asking questions if you don't understand a term or procedure.
- _____ 15. Asking for directions when you are lost.
- _____ 16. Asking for help when you need it.
- _____ 17. Refusing to accept plans or suggestions you feel are inappropriate.

- _____ 18. Telling others at a meeting if you are angry or disappointed.
- _____ 19. Looking and acting self-confident in public meetings.
- _____ 20. Feeling that your opinions are respected by others.
- _____ TOTAL

STOP

ACTION PLAN

1. List 5 of your strengths.

2. List 3 advocacy skills you need to work on.

Complete the following statements:

I am going to advocate for. . .

I prefer to advocate at the (personal, community, state, national) level.

I am going to find support for my advocacy by. . .

PARENT RAP SESSION

Materials Needed

Tape recorder

Microphone

Cassette tape

Time Needed to Complete the Activity

(20-25 min.) Explanation, tape recording

(20 min.) Analysis of the recording

Activity A: What's Wrong with the System?

WHOLE GROUP

Purpose: To give parents an opportunity to express their frustrations with the mental health and special education systems.

Preparation: Have the tape recorder ready to record. Be sure to test the microphone so that you can tell whether it is picking up voices well.

Activity: The facilitator asks the parents if there are things about the mental health system or special education system that have made them angry or frustrated. To stimulate answers, the facilitator may need to give some personal examples like: "I get angry when the social worker implies I have caused by child's problems." "It drives me crazy that there are no day treatment services for my child." The facilitator records his/her response and plays it back for the group. (This is also an opportunity to make sure the tape recorder is working.)

When the group begins to open up and seems ready to share examples, the facilitator asks a volunteer to record his or her example. It is hoped that after someone breaks the ice, all or nearly all of the participants will record their concerns.

Facilitator's Role: The facilitator's role is to establish an atmosphere in which the parents feel free to express their frustrations. Introducing the tape recorder takes some finesse, but, if the facilitator makes him or herself the first guinea pig, usually the group will respond well.

There may be a problem with stopping the group once it gets started. The facilitator should warn the participants when time for recording is about up. For example, the facilitator might say: "We have time for one more message. Does someone have a concern that has not been expressed yet?"

Activity B: Analysis

WHOLE GROUP

Purpose: To identify the problems expressed in each tape recorded message.

Preparation: Rewind tape.

Activity: Each message is played separately. For each one, the group answers the following questions:

What is the problem?

Would a change in the system help to solve this problem?

What systems need to be changed?

Who has the power to change this system? (e.g. legislature, school board, special education director, Federal government).

Does this system have a chain of command? What is the lowest level in the chain? (e.g. teacher, principal, special education director, superintendent, school board).

How could this problem be attacked?

Facilitator's Role: There will not be time to give definitive answers to each of the questions, but the facilitator can help the group to develop a process for seeing problems and finding solutions.

There will probably not be enough time to go through every message, but the process should be done often enough so that all participants understand how to apply the questions to situations.

WHAT IS ADVOCACY?

Materials Needed

Overheads: Packet A

Handouts on Effective Advocacy Techniques

Newspaper article with example of advocacy

Index cards with situations typed on them

Time Needed to Complete the Activity

(20 min.) Presentation on advocacy

(15 min.) Role Play on effective advocacy techniques

(15 min.) Article analysis

Activity A: Advocacy Presentation

WHOLE GROUP

Purpose: To present general information about the concept of advocacy.

Preparation: Have overhead projector ready and focused.

Activity: The facilitator presents to the group a definition of advocacy and makes some remarks about the characteristics and techniques of an effective advocate.

Facilitator's Role: Below is the information that goes with each overhead.

1. "Do we get mad, or do we get even?"

During our rap session, we have seen that all of us have some good reasons for being angry with the system. But it does not do us much good just to get angry. We also must be willing to do something about the things that concern us.

2. Here are some remarks from an angry father:
(Read aloud.)

"It made me so damned mad that my daughter needed help and there just wasn't any available at any price. The only way to get her treatment was to give her up to the state and I wasn't about to do that."

This father has a problem, and he is angry. The question is, though, what is he going to do about it?

3. (Read aloud.)

"Getting mad made me see that something had to be done and that I was the only guy who better do it. No politician was going to care about my child unless I made him do it."

This father sees the problem, but he also sees that he is going to have to do something about it. He is willing to make the commitment to being an advocate for services for his child.

4. "What is advocacy?"

5. Advocacy comes from the Latin *ad vocare* meaning to speak for. An advocate speaks for someone who cannot speak for himself or herself. Lawyers are advocates for their clients. They plead the cause of their clients. Parents can be effective advocates for their children, too. By telling their story and insisting that they be heard, parents can help others to understand and move them to action. Parents can make others care.

6. "What are the qualities of an effective advocate?"

7. An effective advocate is:

FOCUSED: It is impossible to advocate for everyone and for every worthy cause. The effective advocate selects an issue and a group to focus on. For example, a parent might want to advocate for a day treatment program in the local mental health center. Day treatment would be the only issue. The population to be served might be seriously emotionally disturbed children and youth. Chemically dependent or juvenile delinquent youth would not be a focus of the advocacy effort.

INFORMED: To be an effective advocate, the parent must know as much as possible about the issue and about the system that needs changing. Advocates have to research their issues as thoroughly as an investigative reporter.

—ARTICULATE: The advocate's message will not be heard unless it is presented in an effective manner. This means practicing public speaking, writing clear letters, making personal contact with key decision-makers.

COMMITTED: The effective advocate cannot be wishy-washy. He or she must be absolutely dedicated to the advocacy issue and be willing to devote much time and energy to pursuing the issue. Most issues are not resolved quickly, so advocates must be prepared to "hang in there" for a long time.

PERSEVERING: Advocating on mental health issues can be discouraging because the advocate is frequently confronted with negative attitudes and meager financial resources for human services. It takes some stamina and fortitude to continue to pursue an advocacy issue when the goal seems unattainable and there are many defeats along the way.

ASSERTIVE: Advocacy is not for the faint hearted. An effective advocate must be willing to speak up for his or her rights and to make requests firmly and repeatedly until action is taken.

SELF-CONFIDENT: The effective advocate is someone who feels reasonably good about him or herself. An advocate has to be prepared to step forward and take risks.

8. Why is advocacy important?

Leave this overhead on the projector and explain that you hope to answer this question through the activities which follow.

Activity B: Role Play of Effective Advocacy Techniques

WHOLE GROUP

Purpose: To model effective advocacy techniques

Preparation: Practice modeling the situations and techniques listed below. Have situations typed on index cards so that volunteers can read them to the audience.

Activity: The group observes while the facilitator and volunteers from the group act out advocacy situations. This role play demonstrates for the audience a variety of effective techniques for advocating for an issue. One side of the dialogue is someone in the service system denying a service or making a derogatory comment to a parent. The parent then needs to respond in an effective manner. A volunteer reads the situation and the facilitator models effective parent responses.

Facilitator's Role: The facilitator has available index cards with situations on them. Call on new volunteers to read each situation. The following dialogues are examples of what might take place:

—MENTAL HEALTH WORKER: You are making a fool of yourself. You ask for the impossible!

PARENT: (Writing as she speaks). Now, let me see if I've got this straight. You said that I am making a fool of myself. . . that I am asking the impossible.

TECHNIQUE NUMBER 1: Write down a putdown.

The parent should write down (very laboriously) the exact words of the putdown. Seeing this happen makes the professional very nervous. What is the parent going to do with this information? Usually, the professional will backpeddle very fast, retract the put-down and be willing to begin the conversation again.

SCHOOL PRINCIPAL: Are you here again, Mrs. Price? You've been here twice already this week. I can't have you bothering me and my staff all the time.

PARENT: (Not apologizing) It is my understanding that school board policy encourages parents to visit the school. I am observing my son's program so that I have a better idea of what needs to go into his next Individualized Education Program.

TECHNIQUE NUMBER 2: Don't apologize.

The school principal is expecting an apology. He has made it clear that he thinks the parent is out of line. The parent's reply indicates that she sees no need to apologize because she is aware of her rights and she is asserting them.

SCHOOL PRINCIPAL: (In an angry voice) Do you expect us to change the whole school system to accommodate your child?

PARENT: Mr. Singleton, I think it's time we took a break. This meeting is running long. I'd like some time to stretch. Could we come back in a few minutes?

TECHNIQUE NUMBER 3: Take a break.

Mr. Singleton appears to have reached the end of his rope. Further conversation in this vein is not going anywhere. If the principal has a few minutes to cool off, perhaps the meeting can reconvene and the parent can focus the group on the issues again.

SCHOOL PRINCIPAL: We don't have vocational programs for emotionally disturbed students.

PARENT: Who is responsible for vocational programs?

TECHNIQUE NUMBER 4: Find out who is responsible.

This technique is an effective advocacy technique because the parent can go to the person with the power to make decision and make a case for vocational education for emotionally handicapped students.

SPECIAL EDUCATION DIRECTOR: We might be able to begin services next week.

PARENT: Let's set a definite date--next Monday, March 26th--for services to begin.

TECHNIQUE NUMBER 5: Set a deadline.

Promises often are not fulfilled unless definite commitments are made. The parent has set a deadline. Following this conversation, the parent should write a letter confirming the agreement to service on a particular date.

SPECIAL EDUCATION DIRECTOR: The only way you are going to get treatment for your son is by relinquishing custody so he can be placed in a state institution. We can't provide the services he needs here.

PARENT: I'd like a letter from the school district stating that the district does not have a program for my son. I'll send copies of my letter to my son's social worker. I want you to know that we may be pursuing an out-of-district placement in a private school.

TECHNIQUE NUMBER 6: Put it in writing.

This parent is about to take a serious step. She will need evidence that the school district cannot provide an appropriate program. The parent is insisting on having the school district's position in writing. Later, when a case is being made for an out-of-district placement, the parent will have appropriate evidence for the need for the placement.

SCHOOL PRINCIPAL: Mrs. Bartlett, I've heard this argument 10 times and I'm not buying it. You're wasting my time and just making things worse for your son. He's not the only boy I've got in this school!

PARENT: Mr. Nelson, I must repeat that it is my understanding of the law that my son cannot be expelled from school if his handicapping condition is the cause of his misbehavior. You need to call a meeting to determine whether or not his misbehavior is the result of his handicap.

TECHNIQUE NUMBER 7: Repeat your point.

This parent has a good point, and she is correct about how P.L. 94-142 has been interpreted by the courts. She is repeating her point, in spite of the principal's efforts to distract her from the main purpose. If the principal refuses to listen, then she needs to repeat her point at the next highest level in the chain of command.

SOCIAL WORKER: Your daughter seems to have emotional problems. Are you putting too much pressure on her at home? Are there some family problems? Maybe you should get some family counseling.

PARENT: I came to talk to you about my daughter's needs. Let's focus on getting a diagnosis for her and getting her into services.

TECHNIQUE NUMBER 8: Focus discussion.

The parent has returned the focus of the discussion to her daughter's needs, rather than getting sidetracked on concerns about the family.

SOCIAL WORKER: Are you threatening me?

PARENT: No, I'm just making sure I have the correct facts. Here are the facts that I have. Last week, you agreed to call the Probation Office and discuss with my son's probation officer a day treatment program that would meet his needs. The probation officer tells me that you have not called. Are these facts correct?

TECHNIQUE NUMBER 9: Counter emotion with facts.

The parent has ignored the social worker's emotional outburst and has responded, not with emotion, but with a check of the facts.

SOCIAL WORKER: There is no point in trying to work with a case like your son's. His problems are hopeless.

PARENT: You have made a serious judgment about my son. Can you tell me what you have based this judgment on? Is there research to substantiate this judgment?

TECHNIQUE NUMBER 10: Ask for references.

The social worker is closing the book on this case. The parent needs to know why the social worker has made this judgment. Asking for references places a burden on the social worker to come up with a factual basis for writing the child off. Presumably, there are not such "facts," so the conversation can then be turned toward more rational topics.

Activity C: Advocacy Example

SMALL GROUPS

—Purpose: To discover why advocacy can be important.

Preparation: Have articles ready to pass out to each small group.

Activity: The large group is divided into small groups of 4 or 5. The whole group is given a few minutes to read the article. Then each group answers the questions which accompany the article. At the end of the time, the large group reconvenes to answer the general question -- why is advocacy important.

Facilitator's Role: This real example of effective advocacy should provide participants with insight into the value of parent advocacy. Try to draw out the significance of the change that may occur in schizophrenia research as the result of families placing pressure on the federal government.

EFFECTIVE ADVOCACY TECHNIQUES

- 1. Write down a put down.**
- 2. Don't apologize.**
- 3. Take a break.**
- 4. Find out who is responsible.**
- 5. Set a deadline.**
- 6. Put it in writing.**
- 7. Repeat your point.**
- 8. Focus discussion.**
- 9. Counter emotion with facts.**
- 10. Ask for references.**

NEWS

Senator urges boost in research attack on schizophrenia

American brain scientists will declare war on schizophrenia over the next three years, if Sen. Lowell Weicker (R, Conn.) has his way.

On Nov. 20, the outgoing chairman of the powerful Senate Subcommittee on Labor, Health, and Human Services and Education called for a six-fold increase in spending for research on the disease, the symptoms of which include bizarre behavior, hallucinations, and psychosis.

His subcommittee has oversight power over some \$740 million in federal funds spent on research into mental illnesses and brain diseases each year, and critics are charging the National Institutes of Health (NIH) with misdirecting those monies. So Weicker's declaration sent chills through those assembled for a hearing on schizophrenia research. The audience included NIH bureaucrats and members of a growing movement of ex-mental patients and their relatives who are pressing for better treatments for those stricken with the disease.

CREDITING PATIENTS' families with informing him of the pressing need for more schizophrenia research, Weicker told the subcommittee that he "advocates adding \$100 million to the National Institute of Mental Health budget" by 1988 to increase its schizophrenia research.

1. What is the problem of concern to the advocates mentioned in this article?
2. Who are the advocates?
3. What do the advocates want?
4. What did the advocates do to make their point?
5. Would you say that the advocates were successful?

PROBLEMS/SOLUTIONS/POWER

Materials Needed

Index cards with problems on them (1 for each small group)

Worksheets (1 for each small group)

Time Needed to Complete the Activity

(30 min.) Small group work

(15 min.) Large group sharing

SMALL GROUPS

Purpose: To practice the process of identifying the nature of the problem, possible solutions, and sources of power to correct the problem.

Preparation: For each small discussion group, prepare sets of worksheets with the 5 problems.

Activity: The large group is divided into smaller groups of 4 or 5 participants. Each group is given a set of 5 problems to discuss. The group has to decide for each problem: (1) the nature of the problem; (2) some possible solutions to the problem; (3) what agency or individual has the power to solve the problem; and (4) the chain-of-command of the agency where the change must occur. The worksheets should be used to guide the discussion. A recorder in each group can write down the collective responses on the worksheets. Answers cannot be too detailed since the time for this activity is short.

Facilitator's Role: Divide the larger group into small discussion groups. Explain the task and impress on the participants the need to be decisive since time is short.

Circulate among the groups while the discussion is taking place. Model responses for those group that are having trouble getting started.

PROBLEMS/SOLUTIONS/POWER

WORKSHEET

DIRECTIONS: Read the following case studies and answer the questions that follow.

A. Sixteen year-old JOHN has been identified as seriously emotionally disturbed by his school district. He has been staying home from school while the district seeks an appropriate placement for him. It has been a month since John was identified for special education. His mother is concerned because John is difficult for her to control. She is afraid that there will be no school program for him.

What is the problem?

What are some possible solutions to this problem?

What agency or individual has the power to solve this problem?

What is the chain-of-command in the agency that has power over this problem?

What should be the parent's first step in advocating in this situation?

b. MICHELLE, a fifteen year-old sophomore, requires medication and psychotherapy in order to function in her daily life. She qualifies for special education, but the school district refuses to provide psychotherapy because it is a medical service. Michelle's parents are sending her to a psychiatrist, but they feel she also needs counseling in school. They would like the psychiatrist to work with school personnel, so that Michelle has a coordinated program. The psychiatrist is reluctant to interfere in the school program because of previous bad experiences with the high school.

What is the problem?

What are some possible solutions?

What individual or agency has power over this situation?

What is the chain-of-command in the agency that has control over this situation?

What should be the parent's first step in advocating in this situation?

C. MICHAEL has a long history of being disruptive at school. He is a bright student, but his classroom performance has been erratic. Sometimes he makes good grades; other times he is failing all subjects. Michael has no friends at school. Most of the children in his fourth grade class openly express their fear of him. The classroom teacher has told Michael's parents that he is ruining the other children's education because he is so disruptive. Michael's parents have requested that he be tested for special education, but the school has refused because Michael's classroom achievement indicates that he is not educationally handicapped. School personnel have suggested to Michael's parents that they pursue help for him from a community mental health center. The nearest mental health center is 40 miles away. The center currently offers group therapy meetings for teenagers but nothing for elementary aged children.

What is the problem?

What are some possible solutions?

What individual or agency has power over this situation?

What is the chain-of-command in the agency that has power over this problem?

What should be the parents' first steps in solving this problem?

D. LINDA, age 17, has been committed to a state institution for emotionally disturbed youth. In order for her to be committed, her parents had to give up custody. Linda's parents are appalled at the treatment she is receiving in the state institution. They are particularly concerned because she is not receiving any education. Linda's parents cannot afford private treatment for her schizophrenia, but they are now sorry they committed her to this inadequate state facility.

What is the problem?

What are some possible solutions?

What individual or agency has power over this situation?

What is the chain-of-command in the agency that has power over this problem?

What should be the parents' first step in solving this problem?

E. MARY is a beautiful 18 year-old who was a straight-A student until a year ago when she became gradually more and more withdrawn. When her parents noticed this withdrawal, they took Mary to a psychologist who suggested Mary had some adolescent adjustment problems related to her own personal high standards. The psychologist recommended group therapy sessions at the mental health center. Mary attended several group therapy sessions, but her parents saw her condition getting worse rather than getting better. They took Mary to a psychiatrist who hospitalized Mary for two weeks of diagnostic work. At the end of that period, the psychiatrist concluded that Mary was schizophrenic. The psychiatrist recommended that Mary be placed in a private psychiatric hospital. Mary's parents investigated the private facility and found they could not afford it, even with their health insurance paying part of the cost. In the meantime, Mary's condition worsened.

What is the problem?

What are some solutions?

What agencies have power over this situation?

What is the next step for Mary's parents?

What should be done in the short term? In the long term?

ASSERTIVE/PASSIVE/AGGRESSIVE STATEMENTS

Materials Needed

Overheads: Packet B

Assertive/Passive/Aggressive Statements Handouts

Time Needed to complete the Activity

(15 min.) Explanation of assertive, passive, aggressive

(30 min.) Distinguishing assertive, passive and aggressive statements

Activity A: Defining terms

WHOLE GROUP

Purpose: To define passive, aggressive and assertive

Preparation: Prepare overhead projector and screen

Activity: Facilitator explains terms passive, aggressive, assertive using overheads.

Facilitator's Role: Give a short lecture on the terms passive, aggressive, assertive. Overheads are self-explanatory.

Activity B: Distinguishing terms

INDIVIDUAL/WHOLE GROUP

Purpose: To practice distinguishing among passive, aggressive and assertive statements

Preparation: Handouts for this exercise should be in participant packets.

Activity: Participants do the exercise on passive, aggressive and assertive statements, and then the facilitator goes over the answers with the total group.

Facilitator's Role: As you go over the answers to the exercise, there may be differences of opinion about some of the statements. Allow cases to be made for more than one answer. Point out that tone of voice and body language might influence how the statements are interpreted by others.

PASSIVE, AGGRESSIVE AND ASSERTIVE STATEMENTS

DIRECTIONS: Read the statements below and decide if they are assertive (A), aggressive (AG), or passive (P) statements. Next to each statement write A, AG, or P.

- _____ 1. What do you mean my child has an emotional problem? If he has trouble controlling his emotions, it is because you are not handling him right.
- _____ 2. If you don't provide the special education services my child needs and qualifies for, I will ask for a due process hearing.
- _____ 3. I don't think this treatment program is right for my child, but it's better than nothing.
- _____ 4. I don't understand anything about this P.L. 94-142. After all, I'm not a lawyer.
- _____ 5. If I stick my neck out and rock the boat, they'll take it out on my child.
- _____ 6. If they think I'm pushy because I keep asking about services that just means they realize I expect action.
- _____ 7. I've waited long enough. I'm setting a deadline.
- _____ 8. You really don't care about these children. All you care about is your paycheck.
- _____ 9. If there's no money for services, it is because this school district has set other priorities.
- _____ 10. I feel as though I am being blamed for my child's problems. Our focus should be on getting the services my child needs, not on placing blame.
- _____ 11. If you don't give me what I want right away, I'm going to go to the newspapers.
- _____ 12. What I do at home with my child is none of your business.
- _____ 13. Why does it always have to be the parents who get things done?
- _____ 14. I'm too emotional to deal with this. After all, I'm a parent.
- _____ 15. I will obtain outside recommendations regarding my child's needs and request a meeting to amend the Individualized Education Plan.
- _____ 16. I'm not sure I agree with what the professionals are saying, but I feel I had better do what they say.

- _____ 17. Every time I call the doctor's office, he is too busy to talk to me.
- _____ 18. If you suspect my child is emotionally disturbed, I'd like to discuss that with you. When could we have a meeting?
- _____ 19. You haven't done a single thing to help my child. Why don't you get off your duff and do something?
- _____ 20. I believe you took this job partly because of concern for emotionally disturbed children. Therefore, I hope you will help with this problem we are having now.
- _____ 21. I don't care if you do have a program in the public schools. I want my child in a private school.
- _____ 22. It seems that some new methods may be needed to work with my child. Where can we get some technical advice on this problem?
- _____ 23. We parents have worked hard to get laws passed; we intend to see that they are implemented.
- _____ 24. I would like to visit the program in the school before I make a decision whether or not it is an appropriate program for my child.
- _____ 25. The people working with my child are incompetent.

MAKING EFFECTIVE DEMANDS

Materials Needed

Situation/Solution Handouts

Time Needed to complete the Activity

(45 min.) Writing effective demand statements

PARTNERS

Purpose: To practice developing effective demand statements.

Preparation: Be prepared to demonstrate some demand statements if the group is unclear about how to make requests effective.

Activity: The group is divided into partners to develop effective demand statements for five situations. The demand statements should focus directly on the problem and should be properly assertive of the parents' rights.

Facilitator's Role: Reiterate for the group that an effective demand statement should focus on the problem and should assert rights.

Circulate among the groups and assist as necessary.

SITUATIONS/SOLUTIONS

SITUATION: The following statements were written by a social worker in a report sent to the school:

These parents are in great need of counseling. They have unrealistic expectations for their child. Most importantly, they need to improve their extremely negative behavior toward professionals who are trying to help their child.

SOLUTION: What would you say to the social worker about this report?

SITUATION: The Director of Special Education is talking to the parent--

I know your daughter has been out of school for 8 weeks, but that is because we are putting so much effort into planning the perfect special education program for her. You must be patient.

SOLUTION: What would you say to the Director of Special Education?

SITUATION: Your eight year-old son undressed himself in class three times during the past week. The principal says,

Todd's behavior is too bizarre. We just can't handle him in a regular elementary school. You'll have to find some special school.

SOLUTION: What would you say to the principal?

SITUATION: The School Board plans to put the class for emotionally disturbed middle school students in an old junior high school that houses administrative offices but no longer has any students. The chairman of the Board says--

"We'll put the ED class in the old Monroe Junior High. We've got space over there. Some of these ED students are dangerous, so we don't want to mix them in with the rest."

SOLUTION: What would you say to the School Board?

SITUATION: You and the members of the planning team are writing goals for your child's Individualized Education Program. The school personnel want to write goals for a behavior modification program, but they do not want to write academic goals. You are concerned because your child is so far behind in reading and math, yet he has normal intelligence. The teacher says,

"We can't begin to write educational goals until Frank's behavior is under control. We have to concentrate on behavior and let academics go for now."

SOLUTION: How would you convince the IEP team to consider academic goals for your emotionally disturbed child?

ADVOCACY ASSIGNMENTS

Materials Needed

Copies of *How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies* (published by Coordinating Council for Handicapped Children, 407 S. Dearborn, Chicago, IL 60605) for each group.

Assignment sheets for each group

Paper and pencils for each group

Time Needed to complete the Activity

(60 min.) Explanation of the exercise and worktime on assignments

(30 min.) Sharing

Activity A: Advocacy Assignments

SMALL GROUPS

Purpose: To introduce participants to techniques of systems advocacy

Preparation: Have ready a copy of *How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies*, an assignment, and materials for each small group of 4-5 participants.

Activity: The large group is divided into small groups--each with a different advocacy problem. Each group is to devise a plan for pursuing a solution to the problem and to complete some assignments that are part of the plan (eg., writing a letter to the editor).

Facilitator's Role: Carefully explain the instructions to the participants. Ask that each group select a recorder to keep track of decisions.

Circulate among the groups as they work, providing assistance as necessary.

Activity B: Sharing

WHOLE GROUP

Purpose: To share the results of the groups' advocacy assignments.

Preparation: If possible, make copies of the groups written work to share with the whole group.

Activity: The recorder from each group shares their advocacy plans.

Facilitator's Role: Question each recorder to bring out effective techniques, clever wording, examples of appropriate assertiveness. Try to provide only positive comments. Solicit comments from the group at large.

SUGGESTED ADVOCACY ASSIGNMENTS

- 1. Get better teacher aides in the school program for emotionally disturbed children.**
 - A. Make a list of the steps to take in obtaining this goal.**
 - B. Provide an example of a letter to the School Board outlining your concerns.**
 - C. Develop a rebuttal to the Teachers' Union chief who opposes making greater demands on the aides unless they receive better pay.**
- 2. Include emotionally disturbed adolescents in the school district's vocational program.**
 - A. Make a list of the steps to take in obtaining this goal.**
 - B. Develop a rebuttal to parents of regular education students who do not wish their children to associate with ED students in shop classes;**
 - C. Prepare a position statement explaining why ED students ought to have vocational education.**
- 3. Change state law to allow emotionally disturbed youth in state institutions without the parents' relinquishing custody.**
 - A. Make a list of the steps to take in obtaining this goal.**
 - B. Develop a sample letter to your legislator explaining why you support this change in law;**
 - C. Develop a one page fact sheet for legislators that explains the value of parents' retaining custody.**
- 4. Protest cuts by the state legislature of \$30 million dollars in mental health services.**
 - A. Make a list of the steps to take in obtaining this goal.**
 - B. Develop one page of testimony to be presented to the Human Service Committee of the legislature;**
 - C. Make a list of specific ways to involve the media in your protest.**
- 5. Expose the bad conditions in a state institution for the mentally ill.**
 - A. Make a list of the steps to take in obtaining this goal.**
 - B. Write a dialogue for a TV interview on this subject.**
 - C. Write a sample letter to the editor.**
- 6. Protest the lack of educational training in the state training school.**
 - A. Make a list of the steps to take in obtaining this goal.**
 - B. Write a sample letter to the Governor explaining your concerns.**
 - C. Make a plan for personalizing this issue (eg. focusing on the needs of one child caught in this system).**

7. **Develop a campaign to attract a qualified psychiatrist to work at the state institution for the mentally ill.**
 - A. **Make a list of the steps to obtaining this goal.**
 - B. **Identify the obstacles to attracting a qualified psychiatrist.**
 - C. **Write a press release outlining/explaining your goal.**
8. **Promote the location of a model mental health program in your community.**
 - A. **Make a list of the steps to obtaining this goal.**
 - B. **Outline a local media campaign for promoting this campaign.**
 - C. **Develop testimony for a public hearing on this subject.**
9. **Initiate coordination at the state level among agencies that serve children and youth.**
 - A. **Make a list of the steps to obtaining this goal.**
 - B. **Write a letter to the Governor explaining why this coordination is desirable.**
 - C. **Devise some occasion for representatives from relevant agencies to come together to discuss coordination.**
10. **Organize a coalition of parents of children with emotional handicaps.**
 - A. **Make a list of the steps to obtaining this goal.**
 - B. **Develop a letter to parents, inviting them to an initial meeting of the coalition.**
 - C. **Write a press release explaining the purpose of the coalition.**

SELF-ANALYSIS

Materials Needed

Assertiveness Quotient Questionnaires (in participant packets)

Time Needed to complete the Activity

**(15 min.) Analyzing questionnaire responses
Filling out Action Plan**

(15 min.) Group discussion

Activity A: Analyzing Questionnaire

INDIVIDUAL

Purpose: To analyze each individual's potential as an advocate.

Preparation: None

Activity: The facilitator shares with the whole group the following scale:

ASSERTIVENESS QUOTIENT

45 - 60 Ready to Advocate

35 - 44 Need Some Practice

20 - 34 Work on Self-Esteem.

Participants figure their own assertiveness quotient. Each individual is then asked to come up with five strengths they have for advocacy and three areas they need to work on. Each individual then writes his or her own action plan which should include the following:

- 1. I am going to advocate for. . .**
- 2. I prefer to advocate at the (personal, community, state, national) level**
- 3. I am going to find support for my advocacy by. . .**

Facilitator's Role: The facilitator explains that there are many types and levels of advocacy. Individuals need to think about their own interests, strengths and weaknesses and then choose to advocate in the situations where they can be most effective. The Self-Analysis exercise is intended to help workshop participants see their own roles in advocacy.

Activity B: Sharing**WHOLE GROUP**

Purpose: To share comments and concerns resulting from Self-Analysis.

Preparation: None

Activity: The facilitator asks for volunteers to share their Action Plans.

Facilitator's Role: It is important not to insist that everyone share. Some participants will not be ready to say they will be advocates. They should not be forced to make a decision or to share their feelings. Those who feel comfortable about becoming advocates and are willing to speak will be inspiring to the rest.

NOTE: 15 minutes is allotted to this sharing opportunity. If it is going well, allow the sharing to continue for as much as 30 minutes. Then close with the workshop evaluation.

WORKSHOP EVALUATION

Please circle the number which best expresses your reaction to each of the following items:

- | | | | | | |
|-------------------------------------------------------------------|-----------------|---|----------|---|------------------|
| 1) The organization of the sessions was: | Poor
1 | 2 | 3 | 4 | Excellent
5 |
| 2) The objectives of the sessions were: | Vague
1 | 2 | 3 | 4 | Clear
5 |
| 3) The ideas and activites presented were: | Dull
1 | 2 | 3 | 4 | Interesting
5 |
| 4) The workshop facilitators were: | Confusing
1 | 2 | 3 | 4 | Helpful
5 |
| 5) The scope (coverage) was: | Inadequate
1 | 2 | 3 | 4 | Adequate
5 |
| 6) My attendance at this session | No Benefit
1 | 2 | 3 | 4 | Beneficial
5 |
| 7) Overall, I consider this session: | Poor
1 | 2 | 3 | 4 | Excellent
5 |
| 8) Do you feel a need for additional information about the topic? | Yes _____ | | No _____ | | |
| 9) Comments: | | | | | |

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PACKET A OVERHEADS

DO WE GET MAD,

OR DO WE "GET EVEN?"

**It made me so damn mad that my daughter
needed help and there just wasn't any
available at any price. The only way to get
her treatment was to give her up to the
state and I wasn't about to do that.**

Getting mad made me see that something had to be done and that I was the guy who better do it. No politician was going to care about my child unless I made him do it.

WHAT IS ADVOCACY?

ADVOCACY

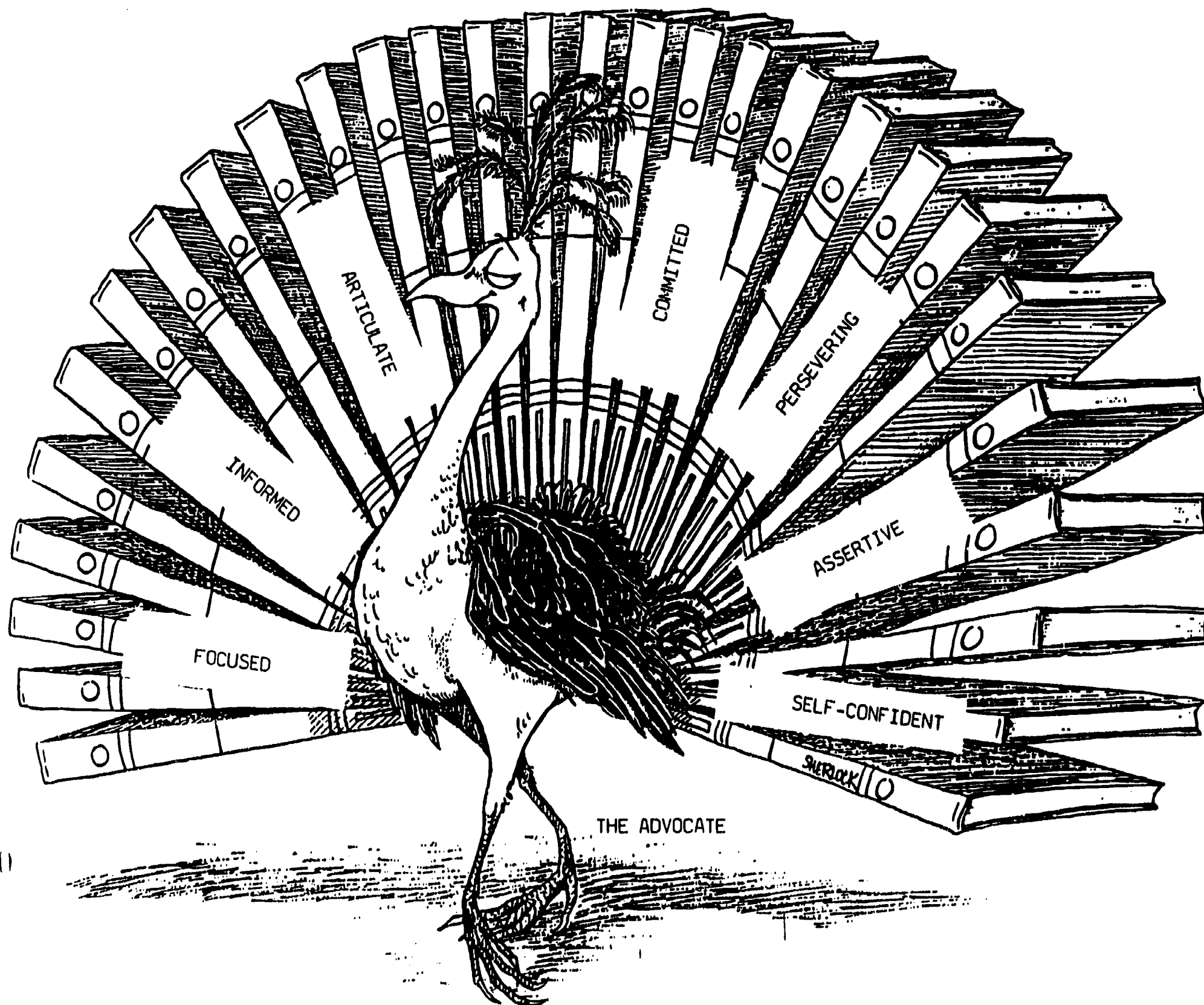
from the Latin, Ad Vocare: to speak for

to plead the cause of another

to make others care

WHAT ARE THE QUALITIES

OF AN EFFECTIVE ADVOCATE?



WHY IS ADVOCACY IMPORTANT?

PACKET B OVERHEADS



A PASSIVE PERSON ...

HOPES FOR FAVORS

RELINQUISHES RIGHTS

VIEWS OTHERS AS SUPERIOR

AVOIDS PROBLEMS

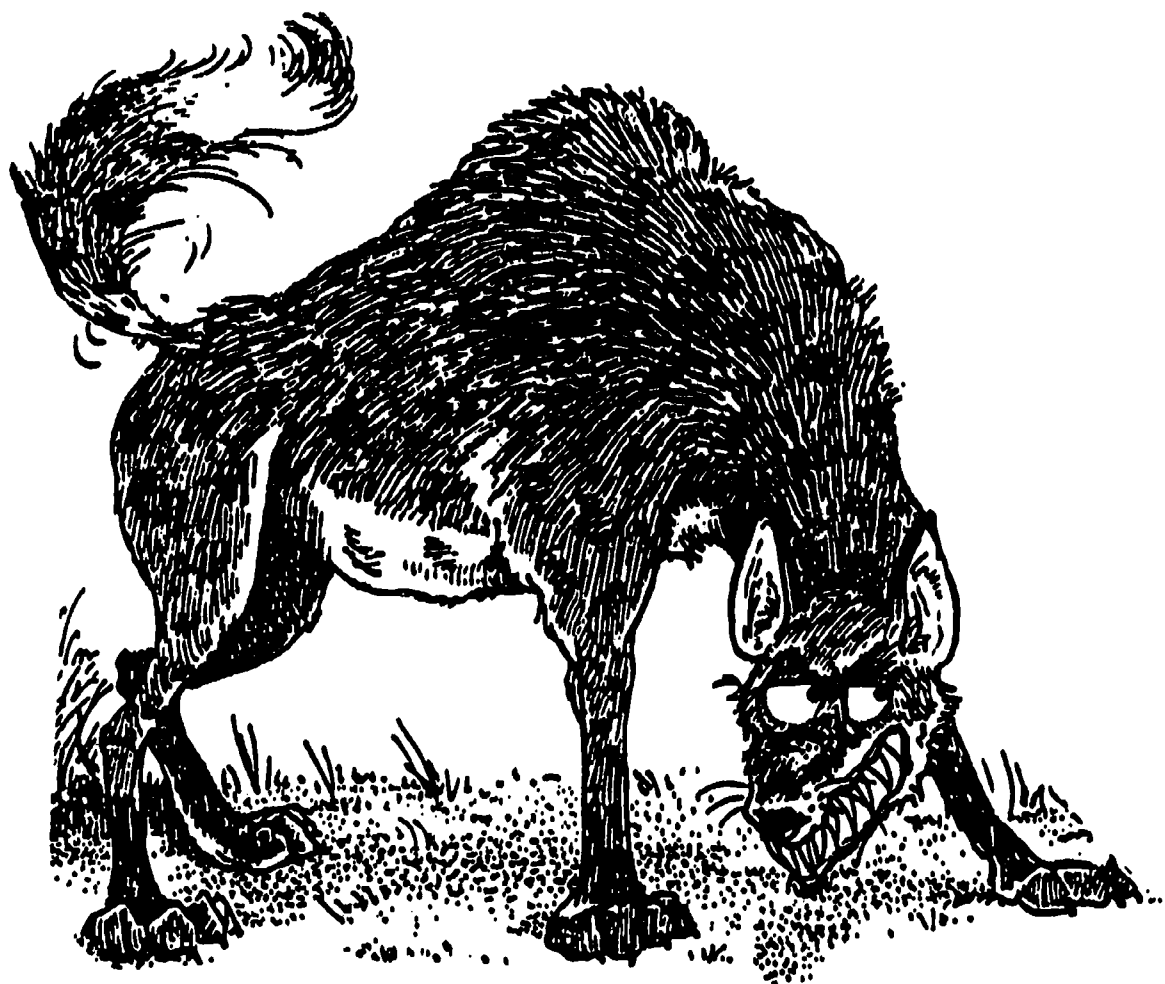
DEFERS TO OTHERS

BOTTLES UP FEELINGS

GETS TAKEN ADVANTAGE OF

HOPES GOALS WILL BE ACHIEVED

LETS OTHERS CHOOSE AND DECIDE



AN AGGRESSIVE PERSON...

ATTACKS PERSONS, RATHER THAN PROBLEMS

DEMANDS RESPECT, BUT LACKS RESPECT FOR OTHERS

VIEWS OWN RIGHTS AS SUPERIOR TO OTHERS

INSTILLS FEAR IN OTHERS

IS DECISIVE AND MAKES CHOICES FOR OTHERS

IS COCKY AND HOSTILE

DEMANDS FAVORS AND SERVICES

AN ASSERTIVE PERSON...

ATTACKS PROBLEMS, NOT PEOPLE

CLAIMS LEGITIMATE RIGHTS

RECOGNIZES THE RIGHTS OF OTHERS

COMMANDS RESPECT AND RESPECTS OTHERS

IS HONEST ABOUT FEELINGS

WORKS TOWARD GOALS

MAKES OWN CHOICES

DEALS WELL WITH ANGER

EXUDES CONFIDENCE

REQUESTS FAVORS AND SERVICES



MAKING THE SYSTEM WORK: AN ADVOCACY WORKSHOP FOR PARENTS
EVALUATION FORM

1. Who used *Making the System Work*? (Check all that apply.)

☐ Parent ☐ Educator ☐ Child Welfare Worker
☐ Juvenile Justice Worker ☐ Mental Health Professional
Other (Please Specify) _____

2. Please describe the purpose(s) for which you used the trainers' guide:

3. Would you recommend use of *Making the System Work* to others? (Circle one)

Definitely Maybe Conditionally Under No Circumstances

Comments: _____

4. Overall, I thought *Making the System Work* was (Circle one)

Excellent Average Poor

Comments: _____

5. Please offer suggestions for the improvement of subsequent editions of this trainers' guide:

We appreciate your comments and suggestions. Your feedback will assist us in our effort to provide relevant and helpful materials. Thank you.

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